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Medical specialists' accounts of the impact of the Internet on the doctor/patient relationship

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ABSTRACT In the context of health service delivery, deprofessionalization denotes a trend towards a demystification of medical expertise and increasing lay scepticism about health professionals, suggesting a decline in the power and status of the medical profession. This process has been linked to increasing consumerism, the rise of complementary medicine and the emergence of the Internet. Drawing on data from in-depth interviews with prostate cancer specialists, this article explores their experiences of the Internet user within the context of the medical consultation. Results suggest that the deprofessionalization thesis is inadequate for capturing the complex and varying ways in which specialists view, and respond to, the Internet-informed patient. It is argued that the ways in which these specialists are adapting to the Internet and the Internet user should be viewed as strategic responses, rather than reflecting a breakdown in their authority or status. 'Enlistment' and 'translation' are presented as useful conceptual tools for understanding specialists' experiences of the Internet.

KEYWORDS *deprofessionalization; doctor/patient relationship; Internet; prostate cancer*

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Introduction

Some social commentators are now arguing that the entrance of the Internet-informed patient, primed with expert/lay/alternative medical knowledge, has considerable implications for traditional patterns within the practice of medicine (Buckland and Gann, 1997; Hardey, 1999; Burrows et al., 2000). A central role of the Internet is as a source of expert knowledge previously inaccessible to the layperson, allowing unprecedented access to alternative and lay knowledges of disease. In this sense, knowledge previously excluded

from public scrutiny is being disseminated, and can, it has been argued, potentially disrupt the expert status of, and professional autonomy of, the biomedical community (Hardey, 1999). As well as the potential for paradigmatic challenge, inspired by Internet-sourced knowledge, the very act of the patient seeking such information independent of the expert contests the traditional biomedical assumption of the patient as recipient of knowledge and expertise (see Broom, 2005a, 2005b).

Despite considerable speculation about the impact of the Internet for the medical profession, no data exist on how specialists view, and are responding to, the Internet-informed patient within the context of the medical consultation (Hardey, 1999). This article, through an examination of the accounts of a specific group of specialists, begins to explore how specialists may experience the Internet-informed patient. It is argued that experiences of the Internet are much more varied than presented hitherto in academic literature, with the results presented below largely contradicting a simplistic power-reduction model. Although further research is needed to explore how specialists actually react in medical consultations, these specialists' accounts provide significant insight into the potential implications of the Internet for the medical profession and, importantly, the potential for the Internet to be used as a tool by medical specialists for increasing patient empowerment and autonomy in decision-making processes.

Background

Theorizing challenges to medical dominance and clinical autonomy

There has been increasing speculation around the deprofessionalization and proletarianization of medicine (Haug, 1973, 1988; Germov, 1995; Slack, 1998; Hardey, 1999; Gray, 2002). Proletarianization has come to represent the process whereby organizational and managerial changes divest professionals of the control they have enjoyed over their work (Hardey, 1999: 821). Deprofessionalization however, in the context of the medical profession, is associated with a demystification of medical expertise and increasing lay scepticism about health professionals (Beck, 1994; Hardey, 1999). This process of deprofessionalization is seen to result from reductions in monopolization of esoteric knowledge, autonomy in work performance and authority over clients (Haug, 1973, 1988). This article examines the extent to which the Internet is playing a role in the deprofessionalization of the medical profession.

A number of social movements and ideological shifts have been linked to this process of deprofessionalization, including the women's health movement (Light and Levine, 1988) and an increase in consumerist approaches to medical care (Lupton, 1997). It has been argued that a 'consumer movement' has been growing for some decades in Australia and overseas (Zadoroznyj, 2001), with, arguably, the potential to undermine the

dominance of orthodox medicine (Haug and Lavin, 1981; Wiles and Higgins, 1996). The proliferation of complementary and alternative medicine (CAM) has to a certain degree catalysed a movement towards a market or consumerist model of health care, increasing the range of options available to consumers, and potentially challenging the monopoly of biomedicine in health care delivery (Bombardieri and Easthope, 2000). Furthermore, the increased consumption of CAM by health consumers has been seen as part of a broader movement towards a questioning of the benefits of the primacy of biomedicine in health provision (Broom, 2002), resulting, for some patients, in increased desire for information and support beyond that supplied by their doctors.

The deprofessionalization and proletarianization theses have been presented as potentially useful concepts for understanding the effects of such developments (Elston, 1991), including the introduction of the Internet as a source of health information and support (Hardey, 1999). In 1988, Haug was already anticipating that new computer technologies would be the major challenge to the power of the medical profession (1988: 54). More recently, some social commentators have been arguing that the Internet is contributing to the evolution of the doctor/patient relationship and the restructuring of the medical profession (Dudley et al., 1996; Hardey, 1999; Ferguson, 2002; McKinlay and Marceau, 2002; Anderson et al., 2003; Nettleton, 2004). The potential of patients to become more informed both about their disease and the performance of their medical specialist is seen to be a new and significant challenge to the classical models of medical care where the doctor is expert provider of information, and the patient is the 'passive' recipient (Hardey, 2002). A number of social commentators have viewed medical dominance as challenged by the exposure of esoteric medical knowledge to the public gaze (e.g. Good, 1994; Hardey, 1999) and by the presence of a wide range of information about, and approaches to, health (Hardey, 1999: 823). This, it is argued, may be contributing to medicine being proletarianized (extended beyond the control of the medical profession) and deprofessionalized (made accessible to the lay-person, thereby reducing the mystique of the medical profession).

Although recent developments such as the proliferation of CAM and the advent of the Internet as a source of information and support may challenge certain facets of health care provision, the question as to whether they have engendered (or even contributed to) the deprofessionalization and proletarianization of medicine is contentious. There are increasing numbers of social commentators who are questioning the notion of the deprofessionalization of medicine or the reduction of medical dominance due to increased consumerism, the proliferation of CAM and the advent of the Internet-informed patient. For example, Lewis et al. (2003) argue that the so-called loss of professional autonomy in medicine may be viewed more as an adjustment to the current social context rather than a breakdown in professional control. Similarly, Germov (1995) suggests that the

theories of increased consumerist approaches, deprofessionalization and reduction in medical power, do not accurately reflect what is actually going on at the point of service delivery. Zadoroznyj (2001) goes further suggesting that despite developments such as the Internet, the increasing prevalence of CAM, and more consumerist models of doctor/patient interaction, the asymmetry in knowledge and power between doctors and their patients remains tilted in favour of the doctors (see also Henwood et al., 2003). As Zadoroznyj points out, people are often distressed when they enter medical encounters, differentiating this encounter from others in the marketplace. This distress is combined, often, with having to undergo potentially humiliating investigations or having to be physically bare in the consultation. Pursuing the view of medical interactions as a 'consumer/provider' relationship is inaccurate in terms of the actual dynamics within consultations (Lupton, 1997). These arguments have considerable implications for the degree to which the Internet, by providing information and support, can impact on doctor/patient relationship, and in turn, the deprofessionalization thesis.

It is argued here that a lack of understanding of medical professionals' experiences of the Internet-informed patient is responsible for the overestimation of the power of the Internet to disrupt traditional forms of care. Michael Hardey (1999: 832) – perhaps the strongest proponent of the view of the Internet as a challenge to medical dominance – states that there is a lack of knowledge about how doctors view or react to Internet usage, especially the strategies clinicians use to adapt to the potential threat of deprofessionalization. Thus it is unclear how these theoretical processes are actually manifested in health delivery, whether they are even occurring at the provider/consumer interaction, and what the implications are for both providers and consumers. It is the aim of this study to begin to fill this gap in current knowledge of the Internet and its effects.

Contextualizing the case study: the 'black box' of prostatic disease

As well as reflecting wider social issues relating to increasingly informed patients and the proliferation of medical knowledge online, the specialists' accounts presented in this article also reflect issues unique to prostatic disease and the men who suffer from it. Although prostate cancer is a major health problem in contemporary Australian society, with steadily increasing morbidity rates and debilitating side effects (Frydenberg, 1998: 11), there exists little agreement about effective treatment within the medical community (Garnick, 1993; NCI, 2003). Added to uncertainty regarding effective treatment, community education programmes are limited and do little to address low public awareness and social support for men with prostate cancer. Public support services lag behind those for breast cancer (PCFA, 2003), with which, considering its prevalence and gender-specificity,

one might make a comparison. Testing procedures are provided on a largely ad hoc basis, are inaccurate and costly (although not dissimilar in accuracy to other screening programmes) and there exists a stalemate between advocates of the PSA (prostate specific antigen) test, and those stoically against it (Andrology Australia, 2004). Furthermore, the causes of prostate cancer remain unclear (Starr, 1998; NCI, 2003), providing men with little guidance on disease prevention. These factors present prostate cancer specialists with the challenging task of managing: inadequate and often conflicting bio-medical sources of evidence; inaccurate testing procedures; inter-speciality conflict (e.g. biases towards surgery or radiation according to speciality); and, patients demanding objective, expert advice on best chance of cure. As evidenced in the following discussion, given these factors, the impact of the Internet may be quite unique in the case of prostate cancer, with men attempting to retrieve as much information as possible about treatment options, and specialists resistant to pushing one treatment programme over another due to ambiguity as to the 'best chance of cure'.

The Australian context for prostate cancer diagnosis and treatment is largely consistent with other countries like the UK and the USA. Men are only tested (for increased PSA levels in the blood) if they are symptomatic or have a family history of prostatic disease. Although men can be treated privately, the health system in Australia is such that quality of care does not differ greatly between the public and private sectors, with many specialists working in both concurrently.

Predominantly older men, prostate cancer patients are a highly specific group of patients. Men in general have a significantly lower level of awareness of the specific risks to their health as compared with women (Court, 1995), and are generally resistant to seeking help for serious medical problems (Cameron and Bernardes, 1998; Tudiver and Talbot, 1999; Walsh, 2000; Broom, 2004). Moreover, men tend to be less able to recognize physical and emotional distress and to seek help (Harrison et al., 1995; Krizek et al., 1999; Saunders, 2000; White, 2002) and may find it more difficult in the medical consultation to question their specialist (Broom, 2005b). This is compounded by the fact that the majority of men with prostate cancer are over 60 years of age – an age group not as accustomed as other groups to taking an active role in their health or treatment decisions (Beisecker and Beisecker, 1990). It has also been shown that physicians often do not deal well with the 'male mentality' (Kiss and Meryn, 2001) and tend to be 'uninformed and uncomfortable with male problems' (Walsh, 2000: 42).

Given historical patterns in advocacy, community support networks and gender ideals, treating an Internet-informed prostate cancer patient will be very different than treating, for example, an Internet-informed breast cancer patient. On the one hand we have a patient group less likely than others to take an active role in decision-making and question medical expertise. On the other hand, we have a disease that presents the patient

with considerable uncertainty and 'gaps' in knowledge regarding best treatment. It is within this context that this study examines the implications of the Internet-informed patient for a specific group of medical specialists.

Method

The interviews

After receiving ethics approval, eighteen medical specialists were recruited from two different states in Australia. The aim was to get a sample including all the specialties for prostate cancer. The final sample included eight urologists, three urological oncologists, three radiation oncologists and four medical oncologists. A mixed sample in terms of gender was not possible as there were so few female prostate specialists and thus the final sample included only one female specialist. Careful analysis of the interview transcripts uncovered no clear differences between her interview and those of the male specialists. The specialists were relatively evenly distributed in age from 40 to 65. The majority of the specialists were recruited via the Victorian Urological Cancer Committee. In total, 40 specialists were sent information letters and 18 eventually consented to an interview. The specialists were interviewed in their medical rooms (the interviews were generally between one and two hours long). All the specialists had had patients who had used the Internet.

The analysis

The methodology for this project draws on the interpretive traditions within qualitative research, focusing on establishing an in-depth understanding of the experiences of the respondents, and in particular, their accounts of the impact of the Internet-informed patient for the practice of medicine. This involved taking an in-depth exploratory approach to data collection, aimed at documenting the subjective and complex experiences of the respondents, rather than merely reflecting on such things as numbers of patients using the Internet, sources of information and the type of information retrieved. The specialists were asked to talk about their attitudes towards, and experiences of, the Internet-informed patient. The focus was on unpacking the complex ways in which the Internet has impacted on their professional identities and practices, building theory from their accounts rather than imposing it on them. Data analysis was based on four questions adapted from Charmaz's approach to social analysis (1990: 1168): What is the basis of a particular experience, action, belief, relationship or structure? What do these assume implicitly or explicitly about particular subjects and relationships? Of what larger process is this action/belief etc. a part? What are the implications of such actions/beliefs for particular actors/institutional forms? As reflected in the structure of the following discussion, dominant themes emerging from the interviews were: the potential of the Internet to be used as a tool for increasing patient autonomy and improving decision-making

processes; the potential role of the Internet in disrupting inter-speciality hierarchies; and, the employment of disciplinary strategies by some specialists to combat the threat of the Internet-informed patient. Although there is considerable heterogeneity within the specialists' accounts, they are broadly characterized by a split between those who supported and encouraged use of the Internet (12 of the specialists), and those who found it largely problematic within the medical consultation (6 of the specialists).

Results

The Internet as enhancing the doctor/patient relationship

As suggested earlier, much has been written about the potential of the Internet, or more specifically, the Internet-informed patient, to disrupt the status and power of the medical professional. However, there has been little consideration of the possibility that some specialists may actually find the Internet a potentially useful tool in clinical practice – that it could be used to improve decision making and quality of care. This possibility, of course, does not sit well with the 'romantic' vision of a crumbling of medical power that underlies much social science health research. Hitherto, no data existed to either back up or contradict whichever position one espoused. This project provided an opportunity to document a group of specialists' in-depth experiences of the information revolution and the Internet-informed patient. In a significant deviation from previous assumptions regarding the impact of the Internet on the practice of medicine, there was considerable support for, and positivity towards, the Internet-informed patient. In the following excerpts three specialists discuss the impact of the Internet on the patient and on the doctor/patient relationship:

My patients in general do use the Internet . . . I consider it part of good medical practice to help patients with the appropriate search engine according to what disease they have. I'm very happy to involve my patients and engage with them and the Internet is a part of that. (Medical oncologist, early 40s, public and private)

[My patients] constantly use the Internet . . . The vast majority of patients with prostate cancer use it. I encourage them to use it and I think they get a lot out of it. It's an important part of medical practice. (Urologist, early 40s, public and private)

I welcome [the Internet]. I have learned a lot from empowered patients pre-Internet and now during the Internet. The Net is a huge source of information and I look at my relationship with patients as a co-partnership. There is no doubt that it can improve your relationships with them. (Urological oncologist, 61–70 years, public and private)

Illustrated in the above excerpts, by taking the approach of fostering their patients' use of the Internet, some of the specialists experienced significant improvements in their relationships with patients. From their perspectives,

the Internet has become an integral part of medical practice, making their jobs easier by allowing their patients to take more responsibility for seeking information. This in turn takes responsibility away from the specialist and gives the patient a greater sense of control. The first respondent stated later in the interview that, 'I am much more comfortable letting them take control and do their own research if it will take some reliance off me'. A common theme in the interviews was that an 'informed' and 'active' patient limited the possibility of blame being directed at the specialist post-treatment if there was dissatisfaction with the treatment or non-treatment outcome.

What emerged from these interviews was a view of the 'active' patient or 'informed patient' as safer than the so-called 'obedient' or 'passive' patient. This seemed to be enhanced in the context of prostate cancer, with several specialists linking the need to involve patients to the lack of certainty regarding cause, treatment side effects and rates of cure. Paternalism and dependency were thus constructed as risk, and maximizing patient autonomy and power within decision-making process as good practice. The medical consultation was viewed as a partnership rather than a process of one-way information provision. The Internet functioned both to empower the patient, and, second, to relieve the specialist of the pressure of being the sole decision-maker.

One specialist outlined his attitude and approach to Internet-informed patients within the medical consultation:

AB: How do you deal with patients that are active or aggressive, wanting to engage as a result of this material from the Internet?

Yeah, it's more of a challenge I guess when people are like that, simply because it's more time-consuming ... patients do need to be the ones making the decisions and my job is to ensure that they have all the information at their disposal to allow them to make an informed decision. And they may, with that information, decide something that I don't agree with, but, that's fine, as long as it's an informed decision, and they are making it on the right basis, then they are entitled to do that and that's OK. So the first thing that I do when I am talking to people is to find out what they already know about their condition. And once I've got some idea from them you also need to find out how much they want to know. (Medical oncologist, 40–50 years, public)

Doctors by and large like to feel completely in control. Well, I'd rather just leave it in the hands of the patient and say, look, you've decided to do this, this is what we're doing, I'll do my best to make sure it's not too toxic for you, but if this happens, I'll help you, you have to call me though. So the onus is on them. It's their health, their thing. It's not my problem – I don't have cancer – I can just advise them, and I think if we have less omnipotence then we would have a lot easier time. (Medical oncologist, early 40s, public and private)

Instead of approaching the consultation as a means of conveying as much information as possible, the first specialist above approaches it in terms of

how much information the patient already has, and, second, how much they wish to receive. Furthermore, he responds to disagreement or refusal to accept his advice by reflecting that 'they are entitled to do that' and later on in the interview that 'that is fair enough'. As shall be illustrated later in this article, the approach of these specialists sits in stark contrast to a number of the other specialists who described the strategies they use to retain control over expert knowledge and the decision-making process. The approach of the first specialist above is reinforced by the second excerpt where this specialist talks about the need for the perception of omnipotence as a serious limitation of modern medicine. For these respondents, the specialist's role is to guide the patient in their decision-making journey rather than take control of the decision-making process. In this way the Internet can contribute to the ability of patients to make an autonomous decision.

Taking this flexible, adaptive approach to the Internet and the Internet-informed patient was not purely about the needs of the patient. Empowering the patient and allowing them an active role in seeking information was also viewed as having practical benefits for medical practice. In particular, and somewhat paradoxically, actively involving the patient and allowing them to feel in control of the decision-making process was viewed as positive for their motivation and thus compliance with the treatment regime:

AB: Does the Internet impact on the medical consultation and if so how?

Look I think it's . . . in general it's a very . . . it's a very good thing because . . . well firstly, it's an identifying issue and the minute you see someone who's got information from the Internet you know that they are likely to be self-motivated, possibly educated, possibly therefore more self-motivated which has compliance issues – it has compliance implications. (Radiation oncologist, around 40 years, public and private)

For a number of the specialists, Internet usage had a positive influence on the doctor/patient relationship because it meant that the patient was likely to approach treatment in a positive and 'compliant way', which, according to the specialist above, is the best possible outcome for him and the patient. From their perspectives, seeking biomedical information from the Internet ultimately was seen to increase motivation to be involved in decision making, increasing understanding of treatment options and possible adverse outcomes. In turn, this alleviates the fear, felt strongly by several of the specialists, of reprisal based on a lack of understanding of the implications of particular treatment options. In the next excerpt one specialist expands on the potential of the Internet to assist in risk avoidance, explaining how the Internet can 'prime' and 'empower' patients, thereby improving the consultation:

An advantage of the Internet is that it can prime people up and in their own leisure they can sit down and they can get a certain amount of information on

a particular disease which then empowers them to ask questions in an informed manner. Because a lot of people will not ask you a question in a consultation because they feel too stupid to ask – they think it's a dumb question or whatever. So if they come pre-primed and they know a little bit about treatment options and comparisons they can be more focused and specific. It makes the consultation a lot easier. (Radiation oncologist, around 40 years, part public and private)

The Internet is experienced by this specialist, and several of the others, as improving the dialogue within the consultation, increasing efficiency as patients have an existing knowledge base thereby allowing a more sophisticated discussion, and lastly, empowering the patient so that they do not feel inadequate within the consultation. As Dudley et al. warn, and the specialist above reinforces, 'passive, malleable patients may not ask many questions, but they assign you extraordinary responsibility for their own health' (1996: 128). As the specialist above suggests, from the perspective of these patients, 'if things go wrong, you assume all of the blame'. This, according to several of the specialists, presents as a considerable risk to them post-treatment (or non-treatment decision). The risk was that patients would rely on them too much and they would therefore be held responsible for any adverse outcomes. According to one of the specialists, to give responsibility to the patient, to allow the patient to do his own research through the Internet, both empowered the patient and reduced the risk of the specialist being held responsible for the treatment decision and thus adverse outcomes.

The accounts of these specialists emphasize the potential of the Internet as a vehicle for increasing patient autonomy, empowerment and allowing the patient to take as much responsibility as possible for the treatment decision. There is an acknowledgement of uncertainty in decision making and the need for co-partnership rather than a paternalistic model of doctor/patient interaction. Promoting use of the Internet, patient control and thus autonomy is seen to reduce the risk for both the patient and the specialist. Moreover, from the perspectives of these specialists, ultimately the outcome is an increase in compliance with the treatment regime selected, maximizing the 'benefits' for the patient.

Inter-speciality competition and the role of the Internet

As seen in the accounts presented earlier, the Internet may actually assist some specialists within decision-making processes. The results of this study also show that it may provide quite unique benefits for *certain* specialists in a socio-historical context of significant inter-speciality competition in the treatment of prostate cancer. As suggested earlier, there is a lack of comparative evidence to weigh up treatment options (Garnick, 1993; Frydenberg, 1998; NCI, 2003), resulting in an ongoing conflict between radiation oncologists and urologists who both offer treatment options for localized disease.¹ Paradoxically, in this context, the role of the Internet is

transformed quite dramatically from being a potential challenge to some medical specialists, to being a means of contesting his or her own professional subordination. One radiation oncologist explains the advantages of the Internet for his speciality, which has traditionally relied on referrals from urologists:

The advantages from a radiation oncologist perspective, given that I'm at the end of the food chain, are that the Internet may allow us to bypass the current hierarchy.

AB: How would it do this?

It will be a medium that educates patients and general doctors to the fact that a urologist is one of a number of health practitioners who have a treatment available for prostate cancer and it might then stimulate perhaps even a direct referral or a patient who asks for a second opinion. You'll be getting more colourful responses from urologists rather than radiation oncologists. The whole idea of the Internet is going to be more challenging in the prostate cancer domain to urologists who have had it really all to themselves for so long. (Radiation oncologist, around 40 years, public and private)

As seen in the above excerpt, and as evidenced in the interviews with the two other radiation oncologists, the Internet allows a medical speciality previously excluded and branded as espousing 'experimental' treatments (i.e. brachytherapy) to have access to prostate cancer patients, or at the very least, to 'market' their treatments to patients who otherwise may not be referred on to them by a urologist. Two specialists reflect on inter-speciality competition and the position of urologists in the current hierarchy in prostate cancer treatment:

There's no question that we urologists are the gatekeepers. We are the people giving the initial information. If you're a surgeon, even if you think you're giving a really balanced view of the options you're going to tend to be a little biased towards surgery ... there is an inherent bias there and I can understand the radiation oncologists' paranoia. (Urologist, early 50s, public and private)

There are urologists who feel that they are giving an unbiased opinion on treatment alternatives. They will say to patients: 'You could have radiotherapy but you've got a 5 per cent chance of having a hole burnt in your bowel and need a colostomy for the rest of your life, but, I mean, if that's what you want, that's fine.' That's the kind of thing they say and it is just not accurate. (Radiation oncologist, around 40 years, public and private)

Within this context of the subordination of radiation oncology as a speciality, the Internet functions to challenge territories within conventional medicine – to disrupt hierarchies and bypass the traditional gatekeepers. It also potentially contributes to the legitimization of radiation oncology as a profession if patients are successfully treated who otherwise would not have been offered radiation therapy. Access to a range of patients (rather than those considered 'bad for surgery') is seen as a vital step by

radiation oncologists in terms of building up 'evidence' that the set of practices they offer are indeed effective in treating localized disease. As seen in the case of CAM (see Broom, 2002), the process of seeking legitimacy is often limited by professional gatekeeping tactics, which seek to reinforce traditional hierarchies though discursive strategies critiquing the legitimacy of the other (e.g. urologists representing radiation oncology as 'unscientific', 'experimental' and 'dangerous'). In terms of the role of the Internet, in this context, rather than disrupting lay/expert, alternative/conventional boundaries, it potentially disrupts established hierarchies within medicine and between medical specialities. However, as evidenced in the following discussion, the Internet-informed patient was not viewed by all the specialists in a positive light.

'Doctor knows best': the Internet as a challenge to expert status

Unlike the specialists seen in the previous sections, several of the specialists experienced significant difficulty with patients who were active, questioning and engaging. This extended to their attitudes towards the Internet and the Internet-informed patient within the medical consultation. Two specialists talked about how they view patients who use the Internet and actively question their decisions:

AB: How do you view patients who actively question your decisions?

I have some trouble. I'm a combative type and in general I get on very well with patients and the nice thing about my patients – and I always say this about prostate cancer patients – is they generally accept what you say, that they respect your decisions and they will go by what you say. So many of my patients will say, 'well, whatever you think is a fair thing, Doc'. I love that, it makes my life much easier. I find, the patients who actually directly challenge me . . . I think a very hard part of clinical practice is dealing with . . . it's not so much the person that asks the intelligent questions, it's the combative question, it's the insinuation that you don't know what you're talking about . . . I find that if a patient says, 'I've got 50 questions to ask you', I can say, 'well, why don't I just tell you what I think is going on, and then you can ask me questions?' and you can generally cover all of those questions before they have even asked them. (Medical oncologist, around 40 years, public, academic)

People are getting information overload. My point is they can't see the wood for the trees . . . I actually prefer to give them something written that I have some control over . . . I'm concerned by the amount of stuff they are given and the Internet is just adding to that because you can tap into the Internet and a 100 pages later or a 1000 pages later or whatever pages later, and how do they digest all that information . . . It can make a consultation go a lot longer though; if you talk about all the different ways that you could be treated and the pros and cons of them it can actually double or triple your consultation. So sometimes it's actually really 'you will have this' [German accent] approach – I dictate the terms. (Medical oncologist, 40–50 years, public)

The aforementioned specialists have clearly established a patient role that they view as normal or good and other patient roles that they view as annoying or irritating. In particular, they prefer the patient who gives them control and power in the medical consultation – the patient who listens and leaves. In a key phrase from the first excerpt, ‘it’s the insinuation that you don’t know what you’re talking about’, this specialist interprets the efforts of patients to equalize the power in the medical encounter as questioning his expertise. If the patient has to talk or ask questions of him, then it is a reflection on his ability – he should be able to provide all the necessary information to the patient without the patient even being involved in the discussion. Like a number of the other specialists interviewed, he uses a number of strategies to maintain control of the consultation if patients do have a number of questions. In his case, if they bring a list, he ensures that he runs the consultation by telling them, “‘why don’t I just tell you what I think is going on, and then you can ask me questions?’” and you can generally cover all of those questions before they have even asked them’. The effect of this strategy is that, inevitably, the specialist does not have time to hear the patient’s questions. He may also be telling the patient what they already know, but because it is only a one-way dialogue at this point, he does not have any indication of the patient’s knowledge base. Furthermore, he does not allow the patient to have a role in the transfer of information by asking the questions that they prepared. The second specialist takes a more direct approach by explicitly saying ‘you will have this’ when things get out of his control. Both specialists, and several others interviewed here, described employing disciplinary strategies such as these to maintain control over the consultation.

In the previous excerpts we can also see a clear preference for prostate cancer patients because of their ‘passivity’ in the medical encounter, and their lack of critical concern for ‘what’s going on’. This preference inevitably becomes determinative. Their choice of disease reinforces the appropriateness and prominence of their preferred patient role. Moreover, the tendency of prostate cancer patients to perform ‘stoical masculinity’ fits in with their preferences, potentially creating a one-way, and for some men, a highly unsatisfactory doctor/patient dynamic. It is likely that very few of their patients explicitly express a desire for more information, and indeed, some may not actually desire more information. However, by normalizing and encouraging submission and passivity in their patients, they potentially alienate those patients who do want to extend beyond the ‘passive role’.

For several of the specialists, the Internet was seen to create confusion and unnecessary discussions in the medical consultation, potentially creating conflict in the doctor/patient relationship. Two specialists talked about ‘information overload’, the ‘dangers’ of the Internet for patients and the implications for the doctor/patient relationship:

They are going to have information overload that they can’t cope with, and then, they come in more confused than when you left them two weeks ago. They’ll

come in to see you with the Internet things this thick [hands a foot apart], and literally they are paralysed. They have no idea where to go because they've just got information coming from everywhere and they can't see the wood for the trees. They literally can't sort of sort it out in their own heads. I think for some people it actually increases stress and actually paralyses them from making a decision. (Urological oncologist, 51–60 years, senior academic)

[Patients] are very vulnerable and I don't think a lot of people are aware that information may not be true or it may be misleading or there may be a commercial interest behind it. But mostly I think they are vulnerable, they're desperate . . . if you give too much responsibility back to the patient do you tip them [over the edge]. (Medical oncologist, 40–50 years, public)

Vulnerability, desperation and incompetence emerged as prominent in some of the specialists' accounts, consistently used rhetorically to justify the danger of the Internet for patients. Some level of confusion may emerge as patients gain access to information via the Internet or other sources. However, the representation of the patient as 'vulnerable' and 'irrational' sits in stark contrast to the accounts of the specialists in the previous section, and furthermore, the author's research on patients' experiences of the Internet (see Broom, 2005a, 2005b). Somewhat paradoxically, the overwhelming theme in the interviews with the specialists in the previous sections was that the Internet allowed patients to 'see the wood from the trees'. It did this by providing the knowledge for them to understand the various treatment options and make an informed decision. It is argued here that representations of patients as 'vulnerable' and 'irrational' have the effect of transforming the potential risk to the specialist (i.e. loss of control or reduction in 'expert' status) into a matter of 'protecting' the patient. Paternalism is thus rationalized as protecting patients from inaccurate information and added 'stress'. Representations of 'the patient' (incompetent/irrational) and 'the Internet' (quackery/chaotic) come together within these specialists' accounts to provide a discursive platform for justifying 'expert' control over decision-making processes, and, effectively, to limit patient involvement and power within the medical consultation. These discursive strategies inevitably have a disciplinary effect within the consultation, encouraging patients to water down their 'challenges' in response to specialist disapproval.

Discussion

Reassessing the deprofessionalization thesis

What do the accounts presented add to the arguments around the so-called deprofessionalization of medicine, and the contribution of the Internet to this process? Thus far two different types of response to the Internet-informed patient have been presented. On the one hand, some of the specialists embraced the Internet and the Internet user, describing improvements in decision-making processes, increased patient autonomy and

agency. Implicit in these narratives was the sense that the result would not be a reduction in support for, or scepticism towards, the clinician, but rather, increased satisfaction with both the clinician and the decision-making process. Thus, we see the potential for the Internet user to be successfully encouraged to be responsible, powerful and autonomous without rendering the specialist's position unimportant or peripheral in the decision-making process. Roles are renegotiated as a result of the Internet-informed patient, but the importance of both subjects within the relationship is retained. Thus, at least at the level of the doctor/patient relationship, specialists may in fact utilize the Internet to improve the practice of medicine and their relationships with their patients. Although the result may be increased understanding (or demystification) on the part of the patient – as per the process of deprofessionalization – the accounts presented suggest that this approach to the Internet user may actually increase support and satisfaction with treatment processes.

On the other hand, we have also seen some specialists describe employing a variety of disciplinary strategies (see Foucault, 1977) to 'cope' with patients who attempt to disrupt traditional lay/expert divisions within the medical encounter. The strategies used by some specialists here to 'discipline' patients who use the Internet inevitably have the effect of retaining expert control over decision making, and in some cases, reconstituting the Internet-informed patient (or indeed, any patient who wishes to engage in the decision-making process) as the passive recipient of medical expertise (see Broom, 2005b). In this way we see different, but also highly problematic, methods of adapting to the challenge of the Internet user within the medical consultation.

Paradoxically, this means that the two forms of power that form the basis of the position of the clinician (expert power and institutional power or the biomedical model) can be bolstered or challenged by the Internet and the Internet user. Taking this into account, it is argued here that, instead of viewing the Internet as contributing to the deprofessionalization of medicine (Hardey, 1999), it should be seen as producing a complex process of adaptation on the part of specialists. In fact, the ways in which these specialists are adapting to the Internet and the Internet user, although at times problematic, should be viewed as strategic responses, rather than a reflection of a breakdown in clinicians' authority or status.

It is argued here that the concepts of 'enlistment' and 'translation' (central tenets of actor-network theory) are useful for understanding the complex relationships between the Internet, the patient and the medical profession. Actor-network theorists have consistently argued for a view of social order as given by the processes of establishing systems of differences, classification and category building, pursuing a relational way of understanding the world (see, for example, Callon, 1986; Latour, 1988, 1993, 1999; Law, 1992, 1994). Their work has focused on the role of the human and the non-human (e.g. devices, texts or objects) in the activity of sorting,

constituting the subject and cementing particular translations of events, entities and actions (Callon, 1986; Latour, 1993). Actor-network theorists have focused on local processes of ordering and resistance – relational processes of translation by which social order is constructed and reconstructed, or put in another way, how durability within a given network is secured (Law, 1992).

Coming from this theoretical tradition, Star and Griesemer (1989) developed the notion of translation as useful in thinking about the ways in which actors (in this case, medical specialists) build support and reinforce their position within a network of actors. 'Translation' here denotes the process by which actors attempt to achieve, consolidate or bolster a position in relation to others within a network, by enlisting and representing particular entities (such as the Internet). This notion of translation refers to the process through which actors negotiate with others within a given network, establishing alignments – a process ultimately involving inscription and modification as actors attempt to 'harden' or contest particular positions. The process of translation inevitably transforms both the enlister and the enlisted. Moreover, the process of enlistment is never secured, and may have multiple and complex effects not necessarily intended by the original action, resulting in an ongoing process to secure a particular translation of an event, entity or actor. Star and Griesemer write about this process, arguing that 'entrepreneurs' gradually enlist participants 'from a range of locations, re-interpret their concerns to fit their own pragmatic goal and then establish themselves as gatekeepers' (1989: 389). In other words, power and status are achieved through a process of strategic response, alignment and ultimately translation.

Specialists, patients, Internet technologies and Internet-based information can be seen as actors whose identities and qualities are defined through processes of negotiation and enlistment. Specialists who perceive the Internet as an inevitable part of their medical practice and/or a potential challenge, will explore ways to enlist (or shape) the Internet to complement their role and reinforce the necessity of their specialized knowledge and skills in decision-making processes. Furthermore, as we have seen, specialists peripherized by a medical hierarchy may enlist the Internet to achieve their own goals of seeking professional legitimacy and reducing their dependency on urological referrals. In this way, the Internet may be viewed as being enlisted and potentially translated by some of these specialists to achieve their own goals – goals that may also be shared by some of their patients. Although this inevitably involves some adaptation on the part of the clinician in terms of their approach to the decision-making process, in large part, their role is retained. Ultimately, this process of translation is one aspect of a strategy to achieve relative durability – to secure uncertain effects or positions within a network (Law, 1992, 1994).

The result of the entrance of the Internet and the Internet-informed patient is increased activity from the medical specialists and the medical

professional as a whole, such as promoting certain websites, setting up regulatory bodies, warning patients away, teaching patients to assess quality and discouraging certain forms of usage (see Gagliardi and Jadad, 2002; Broom, 2005b). This 'activity' is inevitably complex and varied, involving transformation and modification within the development of new professional practices and strategies, as well as new methods of defending, protecting and thus reproducing the 'old'. The Internet and the Internet-informed patient should not be viewed simplistically as challenging medicine or reducing expert status; rather, they should be seen as producing a complex process of adaptation on the part of specialists and their patients. As opposed to the idea of a linear process of deprofessionalization (Hardey, 1999), we see specialists utilizing a variety of strategies to adapt to the entrance of the Internet-informed patient within the medical consultation.

The enlistment of the Internet by specialists should be seen not only as a strategic response to the potential threat of deprofessionalization, but also, a potential movement towards a much more open, dialogical and consultative approach to the doctor/patient relationship and decision-making processes. Thus we see a complex process whereby a mix of interests may be served by a particular action/response, without reducing the process to deprofessionalization or a re-establishment of the expert status.

Conclusion

Due to the fact that actual consultations were not observed in this study, further research is needed to clarify exactly how the accounts given correlate with dynamics within actual medical consultations. A methodological approach that provides a more direct view of interactions within medical consultations, such as conversation analysis, may provide further insight into the impact of the Internet-informed patient for the medical profession. However, at the very least, these results suggest that the impact of the Internet-informed patient may be much more complex than previously argued, and second, that notions of the Internet as a challenge or threat may in fact misrepresent the significant variation in how specialists are experiencing and responding to the health information revolution.

Note

1. As medical oncologists deal primarily with metastatic and advanced disease, they have largely avoided such debates.

References

- Anderson, J., Rainey, M. and Eysenbach, G. (2003). The impact of cyberhealthcare on the physician/patient relationship. *Journal of Medical Systems*, 27(1), 67–84.
- Andrology Australia. (2004). PSA test. *Andrology Australia*. Available at <http://www.andrologyaustralia.org/prostate/psa.htm> (accessed 18 August 2004).

- Beck, U. (1994). The reinvention of politics: Towards a theory of reflexive modernization. In U. Beck, A. Giddens and S. Lash (Eds.), *A reflexive modernization: Politics, tradition and aesthetics in modern social order*, pp. 1–55. Cambridge: Polity Press.
- Beisecker, A. and Beisecker, T. (1990). Patient information-seeking behaviours when communicating with doctors. *Medical Care*, 28, 19–28.
- Bombardieri, D. and Easthope, G. (2000). Convergence between orthodox and alternative medicine: A theoretical elaboration and empirical test. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 4(4), 479–94.
- Broom, A. (2002). Contested territories: The construction of boundaries between alternative and conventional cancer treatments. *New Zealand Sociology*, 17(2), 215–34.
- Broom, A. (2004). Prostate cancer and masculinity in Australian society: A case of stolen identity? *International Journal of Men's Health*, 3(2), 73–91.
- Broom, A. (2005a). The eMale: Prostate cancer, masculinity and online support as a challenge to medical expertise. *Journal of Sociology*, 41(1), 87–104.
- Broom, A. (2005b). Virtually he@lthy: A study into the impact of Internet use on disease experience and the doctor/patient relationship. *Qualitative Health Research*, 15(3), 325–45.
- Buckland, S. and Gann, B. (1997). *Disseminating treatment outcomes information to consumers: Evaluation of five pilot projects*. London: King's Fund Publishing.
- Burrows, R., Nettleton, S., Pleace, N., Pleace, N. and Muncer, S. (2000). Virtual community care: Social policy and the emergence of computer mediated social support. *Information, Communication and Society*, 3(1), 95–121.
- Callon, M. (1986). Elements of a sociology of translation. In J. Law (Ed.), *Power, action and belief: A new sociology of knowledge?*, pp. 196–233. London: Routledge.
- Cameron, E. and Bernardes, J. (1998). Gender and disadvantage in health: Men's health for a change. *Sociology of Health and Illness*, 20(5), 673–93.
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science and Medicine*, 30(11), 1161–72.
- Court, C. (1995). Survey reveals men's ignorance about health. *British Medical Journal*, 310, 759.
- Dudley, T., Falvo, D., Podell, R. and Renner, J. (1996). The informed patient poses a different challenge. *Patient Care*, 30(19), 128–38.
- Elston, M. (1991). The politics of professional power: Medicine in a changing health service. In J. Gabe, M. Calnan and M. Bury (Eds.), *The sociology of the health service*, pp. 58–88. London: Routledge.
- Ferguson, T. (2002). From patients to end users: Quality of online patient networks needs more attention than quality of online health information. *British Medical Journal*, 324(7337), 555–7.
- Foucault, M. (1977). *Discipline and punish: The birth of the prison*. Trans. A. Sheridan. London: Allen Lane.
- Frydenberg, M. (1998). Management of localised prostate cancer: State of the art. *Medical Journal of Australia*, 169, 11–12.
- Gagliardi, A. and Jadad, A.R. (2002). Examination of instruments used to rate quality of health information on the Internet: Chronicle of a voyage with an unclear destination. *British Medical Journal*, 324, 569–73.

- Garnick, M. (1993). Prostate cancer: Screening, diagnosis and management. *Annals of Internal Medicine*, 118, 804–18.
- Germov, J. (1995). Medifraud, managerialism and the decline of medical autonomy: Proletarianisation and deprofessionalisation reconsidered. *Australia and New Zealand Journal of Sociology*, 31(3), 51–66.
- Good, B. (1994). *Medicine, rationality and experience: An anthropological prospective*. London: Routledge.
- Gray, D. (2002). Deprofessionalising doctors? The independence of the British medical profession is under unprecedented attack. *British Medical Journal*, 324(7338), 627–9.
- Hardey, M. (1999). Doctor in the house: The Internet as a source of health knowledge and a challenge to expertise. *Sociology of Health and Illness*, 21(6), 820–35.
- Hardey, M. (2002). ‘The story of my illness’: Personal accounts of illness on the Internet. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(1), 31–46.
- Harrison, J., Maguire, P. and Pitceathly, C. (1995). Confiding in crisis: Gender differences in patterns of confiding among cancer patients. *Social Science and Medicine*, 41, 1255–60.
- Haug, M. (1973). Deprofessionalisation: An alternative hypothesis for the future. *Sociological Review Monograph*, 20, 195–211.
- Haug, M. (1988). A re-examination of the hypothesis of deprofessionalisation. *Milbank Quarterly*, 2(Supp.), 48–56.
- Haug, M. and Lavin, B. (1981). Practitioner or patient: Who’s in charge? *Journal of Health and Social Behaviour*, 22, 212–29.
- Henwood, F., Wyatt, S., Hart, A. and Smith, J. (2003). ‘Ignorance is bliss sometimes’: Constraints on the emergence of the ‘informed patient’ in the changing landscapes of health information. *Sociology of Health and Illness*, 25(6), 589–607.
- Kiss, A. and Meryn, S. (2001). Effect of sex and gender on psychosocial aspects of prostate and breast cancer. *British Medical Journal*, 323(7320), 1055–9.
- Krizek, C., Roberts, C., Ragan, R., Ferrara, J. and Lord, B. (1999). Gender and cancer support group participation. *Cancer Practice*, 7(2), 86–92.
- Latour, B. (1988). *The pasteurization of France*. Cambridge, MA: Harvard University Press.
- Latour, B. (1993). *We have never been modern*. Cambridge, MA: Harvard University Press.
- Latour, B. (1999). *Pandora’s hope: Essays on the reality of science studies*. Cambridge, MA: Harvard University Press.
- Law, J. (1992). Notes on the theory of actor network: Ordering, strategy and heterogeneity. *Systems Practice*, 5(5), 379–94.
- Law, J. (1994). *Organizing modernity*. Oxford: Blackwell.
- Lewis, J., Marjoribanks, T. and Pirotta, M. (2003). Changing professions: General practitioners’ perceptions of autonomy at the front line. *Journal of Sociology*, 39(1), 44–61.
- Light, D. and Levine, S. (1988). The changing character of the medical profession: A theoretical overview. *The Milbank Quarterly*, 66(Supp. 2), 10–32.
- Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science and Medicine*, 45(3), 373–81.
- McKinlay, J. and Marceau, L. (2002). The end of the golden age of doctoring. *International Journal of Health Services*, 32(2), 379–416.

- National Cancer Institute (NCI). (2003). Prostate cancer. Available at <http://www.cancer.gov/cancerinfo/pdq/treatment/prostate/healthprofessional> (accessed 30 February 2004).
- Nettleton, S. (2004). The emergence of e-scaped medicine? *Sociology*, 38(4), 661–79.
- Prostate Cancer Foundation of Australia (PCFA). (2003). Public awareness. Available at <http://www.prostate.org.au/disease.htm> (accessed 18 February 2004).
- Saunders, C. (2000). Where are all the men? *Patient Care*, 34(11), 10.
- Slack, R. (1998). *Cybermedicine*. New York: Jossey-Bass.
- Starr, C. (1998). Prostate cancer: Who's at high risk? *Patient Care*, 32(16), 150.
- Star, S. and Griesemer, J. (1989). Institutional ecology. 'Translations' and boundary objects. *Social Studies of Science*, 19, 387–420.
- Tudiver, F. and Talbot, Y. (1999). Why don't men seek help? Family physicians' perspectives on health-seeking behaviour in men. *Journal of Family Practice*, 43, 475–80.
- Walsh, N. (2000). Men are out of touch with the health care system. *Family Practice News*, 30(20), 42.
- Wiles, R. and Higgins, J. (1996). Doctor–patient relationships in the private sector: Patients' perceptions. *Sociology of Health and Illness*, 18(3), 341–56.
- White, R. (2002). Social and political aspects of men's health. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(3), 267–85.
- Zadoroznyj, M. (2001). Birth and the 'reflexive consumer': Trust risk and medical dominance in obstetric encounters. *Journal of Sociology*, 37(2), 117–41.

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